

SHORT REPORT

# Anosognosia in dementia: A review of current assessment instruments

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## Abstract

**Introduction:** Anosognosia is a common but underrated symptom in dementia and has significant impact on both patients and caregivers. A proper evaluation of anosognosia is therefore desirable. There are three common methods to determine anosognosia: (1) clinical rating, (2) patient-caregiver discrepancies, and (3) prediction of performance discrepancies. Each of them includes different instruments. This review gives an overview of the current instruments used for the assessment of anosognosia in patients with dementia and aims to determine the most suitable instrument for routine use in clinical practice.

**Methods:** A search of the literature in PubMed was performed. Furthermore, electronic databases (PsycINFO, ClinicalKey, and Cochrane Library) and reference lists were searched for additional articles.

**Results:** Forty-six articles were included in this study, comprising 10 clinical rating instruments, 25 patient-caregiver discrepancy instruments, and 14 prediction-performance discrepancy instruments. For every publication, the aims of the study, the included population, the assessment instrument used, the assessed domains, and the psychometric properties of the assessment instruments are described.

**Conclusions:** Currently, there is no consensus on the most suitable method to determine anosognosia in dementia. We recommend the Clinical Insight Rating scale and the Abridged Anosognosia Questionnaire–Dementia as the most appropriate for routine use in clinical practice.

## KEYWORDS

Alzheimer's disease, anosognosia, assessment of anosognosia, dementia

## 1 | INTRODUCTION

Anosognosia, a compound word derived from ancient Greek meaning “lack of knowledge of disease,” was first described by Joseph Babinski in 1914 (translation: Langer and Levine<sup>1</sup>). In the setting of dementia, the phenomenon of anosognosia can be defined as “unawareness of” or

“impaired insight in” the patients' deficits associated with dementia.<sup>2</sup> Anosognosia may occur in multiple domains, such as the illness in general, specific cognitive deficits, affective changes, or activities of daily living.<sup>3,4</sup>

There are three common assessment methods to determine anosognosia in people with dementia:

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1. Clinical rating: this is a quick method in which clinicians make an estimation of the patient's insight.<sup>5,6</sup> Disadvantages may be that the precise procedures vary regarding standardization of the questions (questionnaire, a semi-structured interview, or observation<sup>7</sup>), that categories differ (eg, dichotomous, three-point scale), and that the results are affected by factors relevant to the clinician (eg, experience). Furthermore, the patients' responses may be guided by a desire to present themselves in the best possible way, which could be erroneously interpreted as denial of the problems and subsequently incorrectly termed as anosognosia.<sup>6-8</sup>
2. Patient-caregiver discrepancies: this strategy is based on comparing the patient's self-rating of performance on a functional domain with the caregiver's rating of the patient's performance on the same domain.<sup>5,7,9</sup> Limitations are that it cannot differentiate between participants' overestimation or informants' underestimation. The outcome score may be influenced by participants' ability to use the rating scale, and conversely, the caregiver may not be able to provide an accurate and objective rating.<sup>5,7</sup> Moreover, cut-off scores are mostly arbitrary and validity of the instruments is rarely examined.<sup>6</sup>
3. Prediction of performance discrepancies: this strategy is based on the patient's self-rating regarding the level of performance on a given task. The difference between the patient's own rating and the actual performance score is scored as the degree of anosognosia.<sup>5,6</sup> Disadvantages are that self-ratings are affected by personal factors (such as mood or personality), are time-consuming, and comprise the domain of memory performance only.<sup>8-10</sup>

Each of these methods has its own assessment instruments measuring different domains with their own psychometric properties. At this moment, there is no consensus on the most accurate assessment method or instrument.<sup>8,11,12</sup> More recently, phenomenological and multidimensional methods for in-depth assessment have been developed. These methods attempt to overcome limitations such as the dependence on questionnaire responses. Unlike many other measurement instruments, they take into account multiple domains in which deficits could occur in dementia.<sup>8,10</sup> Phenomenological and multidimensional methods are as yet barely represented in the literature. And because they require a considerable time investment, this limits their suitability for in-depth assessment on the routine use in daily clinical practice. These methods will therefore not be further investigated in this review.

A uniform way to assess anosognosia is warranted for use in clinical practice. Patients with anosognosia present deficits in activities of daily living (ADL), or show changes in behavior such as disinhibition, irritability, and anxiety.<sup>13</sup> Lack of uniform assessment can also hinder treatment as patients who are unaware of their deficits may exhibit reduced therapy compliance.<sup>2</sup> Research shows that anosognosia significantly increases caregiver burden, for example by increasing physical symptoms or social isolation.<sup>14</sup> A proper evaluation of anosognosia by health-care professionals is therefore necessary. In turn, this should lead to person-centered approaches, as understanding the existential world of the patient would make it easier to support patients and their

### Key points

- Anosognosia is a frequent phenomenon in dementia and has significant impact on both patients and especially caregivers.
- Since currently no consensus exists on the most suitable method, we reviewed available assessment instruments to determine anosognosia routinely in clinical practice.
- For this purpose, the Clinical Insight Rating Scale and the Abridged Anosognosia Questionnaire seem the most accurate diagnostic instruments.

### RESEARCH IN CONTEXT

1. Systematic review: We performed a systematic search of the literature, primarily using PubMed. Original quantitative research, opinion papers, or reviews about anosognosia in dementia were included.
2. Interpretation: Because of the significant impact of anosognosia on both patients with dementia and their caregivers, proper evaluation is warranted. Up until now, there is no consensus regarding the most accurate measurement instrument to determine anosognosia in daily clinical practice. In this report, we summarized the current methods for the assessment of anosognosia in dementia and provide recommendations for the most suitable options for routine use in clinical practice.
3. Future directions: Although we propose the Clinical Insight Rating Scale and the Abridged Anosognosia Questionnaire—Dementia as the most suitable for clinical practice, there are still limitations to these measures. The absence of a gold standard precludes the validation of the various assessment instruments. Future research should focus on this.

families effectively.<sup>8</sup> Up until now, there is no consensus regarding the most accurate measurement instrument to determine anosognosia.

In this review, we aim to give an overview of the current instruments used for the assessment of anosognosia in dementia. The primary objective is to answer the following question: Which assessment instrument is the most suitable for use in daily clinical practice?

## 2 | METHODS

A search of the literature was performed, using the PubMed database. The search strategy was developed with help of an information specialist. Relevant index terms and entry terms related to

“Dementia,” “Alzheimer’s disease,” “neuropsychological tests,” “assessment,” “scale,” “agnosia,” “awareness,” and “anosognosia” were selected. Other databases (PsycINFO, ClinicalKey, and Cochrane Library) and the references of relevant articles were searched for additional publications.

The results were screened against the pre-arranged eligibility criteria by one reviewer (NR). The inclusion criteria were: (1) original quantitative research, opinion papers, or reviews; (2) studies on participants with the diagnosis of dementia or probable dementia; (3) measurement tools on anosognosia as intervention; and (4) studies written in English. Exclusion criteria were: (1) other diseases not related to dementia and (2) other impairments not related to anosognosia. After selection of the eligible articles, data extraction was done by one reviewer (NR) and these data were checked by a second reviewer (AS). Any disagreement was resolved by discussion.

### 3 | RESULTS

The PubMed search was conducted in August 2019 and yielded 859 citations. After screening, 46 articles were eligible for this study. For the selected articles, the three common strategies to determine anosognosia in people with dementia were elucidated: 10 clinical rating instruments,<sup>15-24</sup> 25 patient-caregiver discrepancy instruments,<sup>25-49</sup> and 14 prediction performance discrepancy instruments.<sup>32,40,43,50-60</sup> In Appendices I–III in supporting information, a summary of the eligible articles is presented. For every publication, the aims of the study, the included population, the assessment instrument used, the assessed domains, and the psychometric properties of the assessment instruments are described. In general, the study population consisted of patients with dementia. In most studies, the subjects were patients with probable or mild dementia (44 studies). Sample size varied from 12 to 670 patients. Concerning interpretation of the available psychometric data, the general cut-off values were used.

Appendix I presents 10 clinical rating instruments for the assessment of anosognosia. The procedures vary widely: conclusions may be based on a single question,<sup>15,20,22,23</sup> a regular clinical interview,<sup>17</sup> a structured clinical interview,<sup>16,18,19,21</sup> or an observational tool.<sup>24</sup> The rating system differs from a dichotomous outcome<sup>15,20</sup> to a nine-point scale.<sup>16</sup> Regarding domains of assessment, six instruments include multiple domains.<sup>16,19-21,23,24</sup> For these six instruments, psychometric properties were presented, which were all satisfactory.<sup>15-17,19,23,24</sup>

Appendix II describes 25 patient-caregiver discrepancy instruments. In all the studies, assessment of anosognosia depends on the calculation of discrepancy scores between patient and informant/caregiver. There are significant differences in the length of the assessment instruments (when mentioned), varying from 9 items<sup>46</sup> to 108 items.<sup>31</sup> In total, 15 instruments include multiple domains of assessment.<sup>26,29-31,33,34,36,38,41,42,44-48</sup> Some psychometric properties were named for 10 instruments.<sup>29,32,35,38-40,42-46,48,49</sup> The Anosognosia Questionnaire–Dementia<sup>29</sup> has remarkable strong values (intrarater reliability 0.90 to 0.91, internal consistency 0.90 and 0.91).

Appendix III gives an overview of the 14 prediction-performance discrepancy instruments. Many of the presented instruments, eight in total, are based on self-prediction performance on a memory test, compared to actual performance on this test.<sup>32,40,43,51,52,54,56,59</sup> In the other six instruments, multiple domains were assessed.<sup>50,53,55,57,58,60</sup> For only three instruments, psychometric properties were accurately described, all with good values.<sup>40,43,50</sup>

### 4 | DISCUSSION

We aimed to describe the various strategies and instruments used to assess anosognosia in patients with dementia, and determine the most suitable screening instrument for routine clinical practice. Our search of the literature resulted in 46 eligible studies, comprising 49 different assessment instruments.

When determining feasibility for general use in daily clinical practice, an assessment instrument should be quick and reliable.<sup>46</sup> Currently, clinical ratings and patient-caregiver discrepancies can be evaluated relatively rapidly. By contrast, prediction of performance discrepancies are more time consuming, covering the different domains more in-depth. Therefore, we have chosen to look for the most suitable instruments only in the categories of clinical ratings and patient-caregiver discrepancies. Furthermore, we have also placed emphasis on the included domains of assessment. Because anosognosia is a broad concept, good assessment should also involve multiple domains such as the patient’s pattern of activities, emotions, behavior, and social factors.<sup>61</sup>

In the category of clinical rating instruments, only four assessment instruments assess multiple domains and also describe their psychometric properties.<sup>16,19,23,24</sup> One of these instruments<sup>24</sup> was only used in patients with severe dementia and therefore not generally applicable for routine clinical practice. In our opinion, the Clinical Insight Rating Scale<sup>16</sup> seems to be the most suitable option. This instrument is based on a systematic rating scale comprising four different domains, easily identified during a short clinical interview. It also has strong psychometric properties (interrater correlation 0.91, internal consistency 0.85).

Of the described patient-caregiver discrepancy instruments, we found seven assessment instruments with both multiple assessment domains and established psychometric properties.<sup>29,38,42,44-46,48</sup> The instrument with the strongest psychometric properties is the Anosognosia Questionnaire–Dementia (AQ-D; intrarater reliability 0.90 to 0.91, internal consistency 0.90 and 0.91).<sup>29</sup> This instrument measures not only cognitive and functional performance, but also changes in behavior. However, it comprises 30 items and is therefore not suitable for rapid evaluation. We therefore propose the Abridged Anosognosia Questionnaire–Dementia (AAQ)<sup>46</sup> as a suitable alternative for clinical practice. This questionnaire is an abbreviated version of the AQ-D (nine items), still with strong psychometric properties (internal consistency 0.793, validity of the criteria compared to AQ-D 0.800, and area under the receiver operating characteristic curve 0.946).

Our review has some general limitations. Many of the included articles do not present specific data on validity (i.e. sensitivity and

specificity) and psychometric properties (e.g. interrater reliability and internal consistency). This was already mentioned 15 years ago, in the review of Clare et al. which also showed that no uniform gold standard is available against which to measure assessment instruments.<sup>8</sup> Furthermore, our review was not carried out to the standards of a full systematic search, because only one database was searched and only one reviewer selected articles for eligibility (although checked later by a second reviewer). Nevertheless, the present review gives a comprehensive overview of the current assessment tools for anosognosia and their psychometric properties, which has not been done in the last decade.<sup>8</sup>

In conclusion, anosognosia is a common phenomenon in patients with dementia and has significant impact on both patients and caregivers. Currently, no consensus for assessment in clinical practice exists. When comparing the current assessment instruments for anosognosia, we recommend the Clinical Insight Rating Scale and the Abridged Anosognosia Questionnaire–Dementia as the most appropriate for routine use in daily clinical practice.

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## CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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